

2. Ways to Educate Yourself



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Ways to Educate Yourself

What You Can Do

- Use NCI resources to keep up-to-date with new clinical trial information, including *www.cancer.gov*
- Find local clinical trials in your community
- Attend conferences, meetings, and workshops

Why?

- To continue to learn about developments in cancer clinical trials
- To be an informed community educator

Introduction

One of the most important ways to get started in clinical trial outreach and education is to make sure you learn as much as you can about clinical trials. This section describes ways you can learn more about clinical trials.

Education and Outreach in Action

A 60-year-old insurance salesman was treated for prostate cancer 2 years ago. He recently decided that he wanted to learn more about clinical trials after he saw a TV special about them. "I'm amazed about what I don't know about what clinical trials are going on right here in (my community). I want to make sure that men who go to my support group understand information about clinical trials."

1. Use NCI Resources

The NCI Web site, *www.cancer.gov*, contains information from PDQ®, including the latest information about cancer treatment, screening, prevention, genetics, supportive care, and complementary and alternative medicine, as well as a registry of cancer clinical trials. Clinical oncology specialists review current literature from more than 70 medical journals, evaluate its relevance, and synthesize it into clear summaries, which are then reviewed monthly and updated as needed based on new information. Most cancer information summaries appear in two versions: a technical version for the health professional and a nontechnical version for patients, their families, and the public. Many of the summaries are also available in Spanish.

The NCI Web site also includes approximately 100 fact sheets on various cancer-related topics and information on ordering NCI publications, as well as educational features and news summaries concerning the latest results from cancer clinical trials.

The clinical trials registry (PDQ) contains more than 1,800 ongoing clinical trials, with information about studies around the world. All clinical trials undergo review prior to inclusion. Although no single resource lists every cancer clinical trial being conducted in the United States and abroad, PDQ is the most comprehensive cancer clinical trials registry, and contains information about trials sponsored by NCI, the pharmaceutical industry, and some international groups. Users can narrow their retrieval by multiple parameters, such as stage of disease, phase of trial, treatment modality, and geographic location. PDQ also contains an archival file of more than 11,000 clinical trials that are no longer accepting patients, including contact information for the principal investigators of trials that may not yet be published in the biomedical literature.

Accessing Information from NCI

NCI's Cancer Information Service

NCI's Cancer Information Service is a national information and education network for patients, the public, and health professionals. From regional offices covering the entire United States, Puerto Rico, and the U.S. Virgin Islands, trained staff provide the latest cancer information through a toll-free telephone service. Staff can respond to calls in either English or Spanish.

Access

The toll-free number is 1-800-4-CANCER (1-800-422-6237). For deaf and hard of hearing callers with TTY equipment, the number is 1-800-332-8615. Hours of operation are Monday through Friday, 9:00 a.m. to 4:30 p.m., local time. Callers also have the option of listening to recorded information about cancer 24 hours a day, 7 days a week.

CancerNet™ Search Service

This service performs customized PDQ and CANCERLIT® searches for health professionals. Physicians and other health professionals can make requests and receive information through a toll-free telephone service, by e-mail, or by fax.

Access

This toll-free number for the CancerNet Search Service (in the United States) is 1-800-345-3300. Hours of operation are Monday through Friday, 8:00 a.m. to 5:00 p.m., Eastern time. Requests can also be faxed to 1-800-380-1575 (301-897-9563 outside the United States) or sent via e-mail to pdqsearch@cips.nci.nih.gov.

CancerFax®

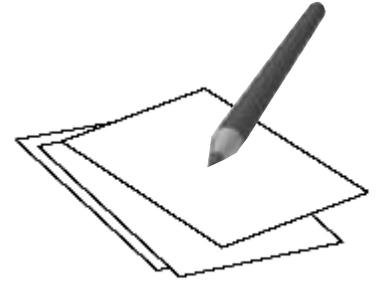
This fax-back document delivery system provides information summaries on cancer treatment, screening, prevention, genetics, and supportive care. CancerFax also includes approximately 100 NCI fact sheets on various cancer-related topics and information on ordering NCI publications. The majority of this information is in English only.

Access

Dial 1-800-624-2511 or 301-402-5874 from a touch-tone phone or from the telephone on a fax machine (the machine must be set to touch-tone dialing). After you reach CancerFax, you will be asked to select either the English or Spanish version. Then, you will hear how to acquire the CancerFax contents list, which provides six-digit code numbers for all of the documents available through CancerFax.

See the guide to clinical trial resources on page 47 for other sources of clinical trial information.

2. Find Local Clinical Trials in Your Community



A good way to educate yourself about clinical trials is to become familiar with both the local institutions conducting clinical trials and the clinical trials themselves. As you begin to think about ways you would like to take action, it will be important for you to understand where clinical trials are taking place.

Creating a List

You may want to create a list that identifies cancer clinical trials in your community. Collecting this information using the “Clinical Trial Community Resource Sheet” provided here can help you direct interested community members to the best clinical trial resources available.

This information can help you:

- Understand clinical research in your community
- Understand some of the barriers to participating in clinical trials in your community
- Provide local clinical trial resources to the organizations or individuals with whom you are working

Clinical Trial Community Resource Sheet

You may use this sheet as a reference for yourself or your organization, or you may develop it into a local fact sheet for distribution. Remember that clinical trial information becomes out of date very quickly, so you will need to update this sheet at least every 3 months. To locate information needed to complete this worksheet, you can:

- Call the National Cancer Institute’s (NCI’s) Cancer Information Service at 1-800-4-CANCER. Trained information specialists can search the NCI clinical trial database, PDQ, and provide contact information for local trials.
- Visit the Web site www.cancer.gov, to search the PDQ database on your own.
- Use the clinical trial resources sheet that follows for other ways to find local trials.

Type of Trial/ Type of Cancer	Phase	Protocol ID#	Institution	Point of contact	Phone number

Guide To Finding Clinical Trial Resources

	What is it?	How do I access it?	What will it provide?
National Cancer Institute's CancerNet/PDQ	<p>Database produced by NCI</p> <p>Registry of approximately 1,800 active cancer clinical trials</p>	<p>Go to www.cancer.gov</p> <p>Go to the clinical trials area and follow the search directions</p> <p>OR</p> <p>Call 1-800-4-CANCER</p>	<p>Summaries about clinical trials conducted by NCI-sponsored researchers, the pharmaceutical industry, and some international groups</p>
National Library of Medicine	<p>Database produced by NIH</p> <p>Registry now lists 4,000 primarily NIH-supported clinical studies on many conditions, and more will be added</p> <p>All trials on PDQ are listed in this database</p>	<p>Go to www.clinicaltrials.gov</p> <p>Can browse by disease or sponsor or insert key words</p>	<p>Summaries about clinical trials for a wide range of conditions—most of the trials listed are sponsored by NIH</p>
Food and Drug Administration's Cancer Clinical Trials Directory	<p>A list of sources prepared by FDA's Office of Special Health Issues</p> <p>Guides user to other Web locations for institutions that conduct or list cancer clinical trials</p>	<p>Go to www.fda.gov/oashi/cancer/trials.html#table</p> <p>Can browse by disease for different sources</p>	<p>Web addresses and telephone numbers</p> <p>Information listed on the Web sites in this directory varies widely</p>
Local Cancer Center Web Sites	<p>Locally produced Web sites that include listings for trials sponsored by NCI and some pharmaceutical companies</p> <p>Good supplementary resources for locating clinical trials; a cancer center may begin participating in an NCI-sponsored trial before the center's information is listed in CancerNet/PDQ</p>	<p>Different sites can be found through:</p> <ul style="list-style-type: none"> • CancerNet/PDQ and National Library of Medicine Web sites • Local institutions <p>Information on trials taking place at NCI's Clinical Center in Bethesda, Maryland, is available at http://ccr.nci.nih.gov</p> <p>Some centers may also have telephone information centers</p>	<p>Information that varies from center to center</p>
Examples of Pharmaceutical Resources/ Internet Clinical Trial Matching Sites	<p>Pharmaceutical Research and Manufacturers of America (PhRMA) publishes a list of new cancer drugs in development</p> <p>CenterWatch's Clinical Trials Listing Service lists many industry- and Government-sponsored trials</p>	<p>PhRMA Go to www.phrma.org/searchcures/</p> <p>Click on "New Medicines in Development" and search by disease. The drugs are listed by cancer type.</p> <p>CenterWatch Go to www.centerwatch.com</p> <p>Click on "Trial Listings"</p>	<p>Descriptions, sites, telephone numbers, and investigator names by State</p>

3. Attend Conferences, Meetings, and Workshops

Some people find that attending scientific meetings keeps them up to date, helping them become better educators.

Local Meetings and Courses

Many local hospitals and cancer centers hold public events, educational workshops, and lectures on a variety of topics related to clinical trials. Contact your local institution's community relations department to find out if it holds such events and when they are scheduled.

Learning through the Internet

Many of the large cancer centers have free online courses for the public, some of which may be related to clinical trials. See the Web site www.cancer.gov for a list of NCI-designated cancer centers and their Web sites to learn more about specific online courses.

National Meetings

Scientists present the results of their research at large meetings before the results are published in the literature. Two annual meetings of importance to cancer research are:

1. American Association of Cancer Research in March of each year (Web site is www.aacr.org)
2. American Society of Clinical Oncology in May of each year (Web site is www.asco.org)

Both feature daily meeting updates on their Web sites.

Many scientific meetings are open and free to the public. Others have reduced fees for survivors or advocates.

The NCI event calendar provides a centralized and easily accessible place to obtain information about many cancer-related scientific meetings and events nationwide. The calendar can be found on the Web at *www.cancer.gov*. You can also call 1-800-4-CANCER to get information about these meetings.

To help you plan educating yourself, see the Plan for Action in the appendix.